HHS Public Access

Author manuscript

Subst Abus. Author manuscript; available in PMC 2016 October 24.

Published in final edited form as:

Subst Abus. 2015 ; 36(2): 144–148. doi:10.1080/08897077.2015.1007202.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Developing a Research Career Focusing on a Stigmatized and Marginalized Population: Sexual Minority Women's Drinking

Tonda L. Hughes, PhD, RN, FAAN[1,2,3]

[1]Department of Health Systems Science, College of Nursing, University of Illinois at Chicago, Chicago, IL, USA

[2]Global Health, College of Nursing, University of Illinois at Chicago, Chicago, IL, USA

[3]Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program, University of Illinois at Chicago, Chicago, IL, USA

I am deeply honored to have been selected for the Betty Ford Award, an award that recognizes her contributions to the advancement of substance abuse treatment for women. Betty Ford was a woman who understood stigma—and who understood that the most effective way to reduce stigma is to bring it out into the open. From being one of the first people to publicly use the words "breast" and "cancer" in the same sentence, to her disclosures about seeking psychiatric treatment to deal with stress, and her acknowledgement that she was addicted to alcohol and prescription drugs—Betty Ford changed societal attitudes and helped pave the way for more compassionate health care for thousands of women (and men). She was the personification of a risk taker and a powerful advocate for marginalized population groups. Although I knew about Mrs. Ford's strong support of equal rights for women, I didn't know until recently that she also championed the rights of lesbian, gay, bisexual and transgender people. She was among the first of the Republican Party to speak out with compassion about people with AIDS and in 1985 she was given the first *AIDS Project Commitment to Life* Award. Betty Ford was also vocal about her support of gay and lesbian rights in the workplace—and was among the first public figures to take a stand in support of same-sex marriage. I'd like to believe that Betty Ford is pleased to know that this year the award named in her honor recognizes work that continues her legacy of making visible women who are stigmatized and marginalized.

Preparing this presentation provided a wonderful opportunity to reflect on my 25 years as a nurse researcher—and especially on my research related to sexual minority women's (SMW) drinking. This afternoon I'd like to take you on a brief journey of how I got to where I am today, highlighting some of the interesting findings from my work as well as some of the "bumps" I've encountered along the way.

Correspondence should be addressed to Tonda L. Hughes, PhD, RN, FAAN, University of Illinois at Chicago, College of Nursing (M/C 802), Chicago, IL 60612-7350, USA. thughes@uic.edu.

The Association for Medical Education and Research in Substance Abuse (AMERSA) Betty Ford Award is given annually to an individual who has played a significant role in the treatment and recovery of individuals with substance use disorders, especially women. The 2014 Betty Ford Award winner was Dr. Tonda Hughes, who presented her plenary on November 6th, 2014.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

My focus on sexual minority (SM) health research began in the early 1990s. I'd been doing research related to women's health for several years and I'd learned that much of the research until that time had focused on men and had been conducted by male researchers. Consequently, much of what we knew about many diseases and risk factors was based on the experiences of men. In 1990, the Government Accounting Office criticized the National Institutes of Health (NIH) for excluding women from most studies involving diseases, treatments, and drug effects and for devoting only 13% of its research funds to women.[1] In 1993 NIH began requiring that researchers include women in all human subjects research—or provide a strong rationale for why this was not appropriate.[2]

It was around this time when I learned that just as women had been left out of much of health research in general, SMW were being excluded from research on women's health. A review of the literature published a decade later illustrates this gap. Between 1980 and 2000 only 0.1% of articles indexed by Medline addressed SM health. Most of these articles focused on gay/bisexual men and addressed primarily sexually transmitted infections, particularly HIV. Lesbian/bisexual women were included in only about one-third of the 0.1% of articles.[3] Similarly, between 1989 and 2011, apart from studies of HIV/AIDS, only 0.1% of all NIH-funded studies focused on SMs. Of these most focused on men, with only 13.5% addressing SMW's health.[4]

Prior to 1980, the few studies of SMW's health largely focused on alcohol use.[5] However, because of the difficulty finding SMW to participate in research, nearly every early study recruited some or allof its sample from gay bars.[6,7] Not surprisingly these studies found high rates of alcohol abuse and alcohol-related problems. My work over the past 20–25 years reflects my attempts to provide a fuller and more scientifically rigorous understanding of SMW's drinking—including both risk and protective factors.

None of us got to where we are today through hard work alone—and I am certainly no exception. I would not be at this point in my career were it not for the mentors that I've had along the way. In addition to my academic mentors, I owe a great deal to my parents. I grew up in rural South-Eastern Kentucky, in the foothills of the Appalachian Mountains. I'm the daughter of a coal-mining father and "jill of all trades" mother, neither of whom went to college but both of whom were the biggest proponents of my education. I completed my undergraduate work at Eastern Kentucky University and my master's degree in community mental health nursing at the University of Kentucky (UK), where I had two wonderful mentors: Drs. Gretchen LaGodna and Melba Jo Hendrix. This program changed my world view—and set me on a research career path focusing on substance use among women. Later, after I'd joined the nursing faculty at UK, Gretchen and Jo were approached by the Kentucky Board of Nursing to develop a program to help nurses who had problems related to alcohol or other drug use. In this program—which we called Nurses Assisting Nurses—participants received counseling and took part in a research study aimed at understanding risk factors for alcohol and drug abuse among nurses. Many nurses who completed the program were able to return to their previous employment. This was a major improvement, because at the time there were almost no programs or policies related to "impaired nurses," even though similar programs for physicians had been around for a number of years. Nurses were typically fired from their jobs and left with few resources with which to seek help.

Author Manuscript

I applied to the University of Illinois at Chicago (UIC) for my PhD because of its strong women's health program. Those were exciting times because the women's health movement had just begun—and nursing academics were in the forefront of the movement. A number of UIC faculty members, including my mentors Drs. Beverly McElmurry, Denny Webster and Alice Dan were key players in redefining women's health from a focus on reproduction to the perspective of women as holistic beings who are experts on their own health. During my doctoral studies I served as Associate Editor of a UIC publication called *Women's Health Nursing Scan*, and co-edited a book titled *Addiction in the Nursing Profession* and a special issue on women's health in *Nursing Clinics of North America*. These activities delayed completion of my degree but were important in the development of my research career, including being invited to join the College of Nursing faculty at UIC.

Early in my employment at UIC I received an individual post-doctoral fellowship from the National Institute on Drug Abuse which allowed me to expand my research skills and expertise in substance abuse among women. The fellowship also provided important opportunities to attend conferences and to network with leading researchers in the field. It was these experiences that led to my discovery of the huge gap in knowledge about lesbian health. At the time there was so little information available that I quickly became a spokesperson for lesbians' use of alcohol—providing testimony to the Institute of Medicine's Committee on Lesbian Health and serving on several federal advisory committees that were working to include lesbians in their priorities and plans.

It was also during this time that I met Dr. Sharon Wilsnack, an internationally renowned researcher (and 1991 Betty Ford Award recipient). Sharon was conducting a 20-year longitudinal study of alcohol use among women in the US general population. I asked Sharon if she would co-author an article on lesbians' drinking for *Alcohol Health and Research World*,[8] and we have been close collaborators since. Sharon's reputation lent a great deal of credibility to my early research, which was particularly important given the stigma associated with minority sexual orientation.

Although I wasn't aware of it early in my career, my research has always been based on principles of health equity and social justice—perspectives critical to research with stigmatized and marginalized population groups. In 76 countries throughout the world same-sex relationships are currently criminalized[9]—and in at least 10 counties SM people can legally be put to death.[10] Although a great deal of progress has been made recently, especially in the US and other Western countries, there is still much to do in terms of social justice and health equity for SM people. For example, in 29 states in the US it is legal to fire an employee for being 'out' as lesbian, gay or bisexual in the workplace; in 34 states employers have the legal right to fire people who are transgender.[11] Although SM people make up about 4% of the U.S. population, 19% of all reported hate crimes target SMs—and hate crimes perpetrated against SM people tend to be much more violent than those that target other minority groups.

Among the most violent forms of hate crimes against SMW is a form of gender-based homophobic sexual violence called 'corrective rape,'[12] intended to convert lesbians to heterosexuality—to 'cure' them of being gay. Women whose appearance does not fit

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

traditional female gender-role norms are particularly targeted. Corrective rape has gained the most attention in South Africa, where it is estimated that at least 10 lesbian women per week are assaulted in Cape Town alone,[13] but it has also been documented in other countries—including the US and Canada. Unlike many other countries on the Africa continent that have extremely oppressive anti-gay policies in place, South Africa has very progressive policies regarding SMs. It was the first country in the world to include protection for sexual minorities in its constitution and the fifth country to legalize same-sex marriage. However, as demonstrated in South Africa, such supportive policies do not necessarily translate to civil rights and legal protections for sexual minority people.

Although rape and murder are among the most serious forms of violence perpetrated against SMW, research that I have conducted or collaborated on has consistently found that rates of almost all forms of violence and victimization—whether sexual or physical and whether in adulthood, adolescence or childhood—are substantially higher among SMW women than among heterosexual women.[14–16] (also Szalacha et al., unpublished data, 2013)

For example, my earliest research on SM health was a lesbian health needs assessment conducted in the Chicago metropolitan area. In this study, twice as many lesbians as matched heterosexual controls reported having experienced childhood victimization.[17,18] As a follow-up, we expanded this study to include 3 other cities in the US where we also found elevated rates of both childhood and adult victimization among SMW.[19]

Concurrent with these studies I began developing my own research project—the *Chicago Health and Life Experiences of Women* (CHLEW) study. The CHLEW was designed to replicate Sharon Wilsnack's *National Study of Health and Life Experiences of Women* (NSHLEW). With funding from the UIC College of Nursing and the UIC Campus Research Board, I adapted and pilot-tested the NSHLEW instrument which I used in my first major NIAAA grant—a Mentored Research Career Development award.

This grant was funded in 1999, the same year that the Institute of Medicine (IOM) published its landmark report on lesbian health research.[20] The CHLEW study was designed to address the major methodological limitations identified in the IOM report—including the lack of appropriate heterosexual comparison groups, the predominant focus on white, middle-class and relatively young women, and the lack of longitudinal studies. We were successful in reaching a diverse sample of 447 women that included sizable numbers of older women, lower-income women and women of color—groups that were grossly under-represented in previous research with SMW.

Among the most interesting findings from this phase of the CHLEW study was that, unlike in the general population where white women are more likely than Black or Hispanic women to drink and to drink heavily, we found that Black SMW were significantly more likely than their white counterparts to report heavy drinking.[21] In analyses of the combined CHLEW and NSHLEW samples, we found that SMW showed lower and slower age-related declines in drinking than did heterosexual women.[22] This longer exposure to alcohol consumption among SMW is important because it increases risk of chronic alcohol-related health conditions, such as cardiovascular disease and some cancers.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

The CHLEW study is now in its 15th year. We have been fortunate to receive two additional NIH/NIAAA R01 grants (and two administrative supplements) to expand and continue the study—making it the largest and longest running study of SMW's health drinking in the US or elsewhere. We recently completed the 10-year follow-up assessment with 79% of our original sample (7% of participants are deceased). We also added a new sample of younger (18–25 years), Black and Latina, and bisexual women (total N=373). In addition to examining changes in risk and resiliency over time, we are now focusing on the accumulated impact of lifetime victimization and SM-specific stressors (e.g, discrimination) on hazardous drinking (HD) and depression.

I have also been fortunate to be involved as PI or Co-I on a number of other large studies—including several secondary analyses of general population surveys in Australia and the U.S., and several studies using non-probability samples of SMW. I'd like to highlight just a few of the most interesting and important findings from the CHLEW and these other studies.

As mentioned before, one of the most important findings of my work is SMW's high rates of lifetime victimization. In both the CHLEW and in secondary analyses of the National Epidemiologic Survey of Alcohol and Related Conditions (NESARC) and the Australian Longitudinal Study of Women's Health (ALSWH) we have found rates 2–3 times higher than those of heterosexual women.[23] (also Szalacha et al., unpublished data, 2013) In addition, childhood victimization—both physical and sexual abuse—appears to be substantially more severe among SM than among heterosexual women.[24,25] I believe that these findings reflect an important and previously under-recognized source of SMW's elevated rates of substance use and mental health problems.

Also important are findings of wide variations across subgroups of SMW. When I first began my research, bisexual women were almost entirely invisible. In fact, too little was known to include them in the 1999 IOM report on lesbian health.[20] In combined data from the CHLEW and the NSHLEW samples we have found that risk behaviors and health outcomes vary substantially across SM subgroups—and, that bisexual women tend to have the highest risk profiles and show the poorest health-related outcomes.[26] In contrast, our work has shown that SMW who identify as lesbian and report only lifetime female partners do not differ from heterosexual women on drinking and many health outcomes. (Everett et al., unpublished data, 2014)

Using questions that ask SMW to rate themselves on a scale of how feminine or masculine they perceive themselves to be, we've found that higher femininity scores are associated with lower levels of discrimination and victimization, but higher levels of depression and internalized stigma. In contrast, SMW who rate themselves as more masculine have lower levels of internalized stigma, but higher levels of discrimination, victimization, and HD. (Everett et al., unpublished data, 2014)

The CHLEW and NSHLEW are among relatively few studies that include sexual identity response options that go beyond asking a woman whether she identifies as heterosexual, bisexual, or lesbian. By doing so we have found that women who choose the intermediate option of "mostly heterosexual" differ from exclusively heterosexual women on a variety of

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

health outcomes. For example, using data from the NSHLEW we found that mostly heterosexual women are 2–4 times as likely as exclusively heterosexual women to report nearly every alcohol and drug use outcome assessed (Hughes, Wilsnack and Kristjanson, unpublished data, 2014). We have found similar disparities in the ALSWH—not only for substance use but also for multiple mental health indicators.[15] I was recently asked to provide testimony at an NIH listening session that emphasized the importance of expanding sexual identity questions to include a mostly heterosexual response option. I believe that until this happens we will continue to underestimate the health risks of this group and that health care providers will miss important opportunities for health education and counseling.

The CHLEW was among the first studies of SMW to assess all 3 major dimensions of sexual orientation. We have found that women whose sexual identity matches their sexual behavior (e.g., women who identity as lesbian and have sex only with women) are at lower risk for hazardous drinking than those whose identity doesn't match their behavior or attraction (Talley et al., unpublished data, 2014). We have also recently discovered that women whose sexual identity remains stable have lower risk profiles than those whose identity changes over time, and this appears to be true regardless of whether the change is in the direction of more same-sex orientation or more opposite–sex orientation (Everett et al., unpublished data, 2014). These findings suggest that having an identity that is stable, consistent and validated by others is important for SMW's health and well-being.

We have clearly come a long way from the time when what we knew about SMW's drinking came almost entirely from samples recruited in gay bars and when minority sexual orientation was a diagnosable mental disorder, but we have yet to fully understand the underlying causes of sexual-orientation related health disparities. Over the past several years a number of states—including Illinois—have expanded the legal rights available to couples in same-sex relationships by legalizing civil unions, domestic partnerships—and more recently, same-sex marriage. We were fortunate that one of these changes—the *Illinois Religious Freedom Protection and Civil Union Act*—occurred during our last wave of CHLEW data collection after we had interviewed about one-half of our 727 participants interviewed in 2010–2012. This law granted same-sex couples many of the rights of marriage. When we compared participants interviewed before and after the bill passed we found a number of differences that seem to reflect significant improvements in the mental health of all SMW (whether in same-sex unions or not). For example, SMW interviewed after the bill's passage reported lower levels of stigma consciousness (the belief that others view them in stigmatizing ways), perceived discrimination, depressive symptoms—and lower levels of HD—than those interviewed before the bill passed. Interestingly, we found that these benefits were concentrated among Black and Latina women and women without college degrees—suggesting that SMW who are more marginalized may reap greater benefits from these supportive policies (Everett, Hatzenbuehler and Hughes, unpublished data, 2014).

We recently submitted a renewal grant application to NIAAA to capitalize on an even bigger policy change. In June 2014, Illinois became the 16th state in the US to legalize same-sex marriage. Because we have CHLEW data prior to when same-sex marriage was legally recognized (and prior to when civil unions were legal), we are positioned to conduct a

natural experiment to evaluate the effects of these historic policy changes on the health and well-being of SMW, including their drinking behaviors.

In addition to new discoveries that are shaping societal attitudes, public policy and clinical practice, one of the most rewarding aspects of my work is that it provides an opportunity to give voice to a group that is largely invisible and to feel that I am making a difference. These intrinsic rewards have gotten me through some rough spots in my career—such as early on when I was advised by senior colleagues not to focus on SMW's health (at least not until I had tenure)—and later in 2003 when the CHLEW project turned up on a 'hit list' of NIH-funded research projects generated by a conservative religious coalition.[27] This group claimed that researchers on the list were conducting prurient health research and demanded that NIH provide a written explanation of any benefit that could possibly be derived from these projects. The list included studies on HIV prevention and adolescent sexual behavior, among others. My study was included presumably because it included the word 'lesbian' in the title. Although I was in good company with researchers from Brown, Johns Hopkins and elsewhere, the effects were chilling.

Despite these small and manageable difficulties, I feel extremely fortunate to be living in this time of historic changes and to have the opportunity to contribute to the advancement in knowledge about SMW's drinking and health. It is my most sincere hope that I am around to see the total eradication of health disparities based on sexual orientation in my lifetime.

References

1. Auerbach JD, Figert AE. Women's health research: Public policy and sociology. J Health Soc Behav. 1995:115–31. [PubMed: 7560844]
2. National Institutes of Health. Revitalization Act. 1993. http://grants.nih.gov/grants/guide/notice-files/not94-100.html. Accessed November 22, 2014
3. Boehmer U. Twenty years of public health research: Inclusion of lesbian, gay, bisexual, and transgender populations. Am J Public Health. 2002; 92(7):1125–30. [PubMed: 12084696]
4. Coulter RW, Kenst KS, Bowen DJ. Research funded by the national institutes of health on the health of lesbian, gay, bisexual, and transgender populations. Am J Public Health. 2014; 104(2):e105–e112. [PubMed: 24328665]
5. Hughes T. Alcohol use and alcohol-related problems among sexual minority women. Alcohol Treat Q. 2011; 29(4):403–35. [PubMed: 22470226]
6. Fifield, LH.; Latham, JD.; Phillips, C. Alcoholism in the gay community: The price of alienation, isolation and oppression. Los Angeles: Gay Community Services Center; 1977.
7. Saghir, MT.; Robbins, E. Male and female homosexuality: A comprehensive investigation. Baltimore: Williams & Wilkins; 1973.
8. Hughes TL, Wilsnack SC. Research on lesbians and alcohol. Alcohol Health Res World. 1994; 18(3):202–205.
9. Stewart, C. Erasing 76 crimes. http://76crimes.com/76-countries-where-homosexuality-is-illegal. Updated October 16, 2014. Accessed November 22, 2014
10. Rupar, T. Here are the 10 countries where homosexuality may be punished by death. Washington Post. February 24, 2014 http://www.washingtonpost.com/blogs/worldviews/wp/2014/02/24/here-are-the-10-countries-where-homosexuality-may-be-punished-by-death/. Accessed November 22, 2014
11. Human Rights Commission. Employment non-discrimination act. http://www.hrc.org/resources/entry/employment-non-discrimination-act. Updated June 2, 2014. Accessed November 22, 2014

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

12. Seedat M, Van Niekerk A, Jewkes R, Suffla S, Ratele K. Violence and injuries in South Africa: Prioritising an agenda for prevention. Lancet. 2009; 374(9694):1011–22. [PubMed: 19709732]
13. Fihlani, P. South Africa's lesbians fear "corrective rape". BBC News. Jun 29. 2011 http://www.bbc.com/news/world-africa-13908662. Accessed November 22, 2014
14. Drabble L, Trocki KF, Hughes TL, Korcha RA, Lown AE. Sexual orientation differences in the relationship between victimization and hazardous drinking among women in the National Alcohol Survey. Psychol Addict Behav. 2013; 27(3):639–48. [PubMed: 23438246]
15. Hughes T, Szalacha LA, McNair R. Substance abuse and mental health disparities: Comparisons across sexual identity groups in a national sample of young Australian women. Soc Sci Med. 2010; 71(4):824–831. [PubMed: 20579794]
16. Hughes TL, Johnson TP, Steffen AD, Wilsnack SC, Everett B. Lifetime victimization, hazardous drinking, and depression among heterosexual and sexual minority women. LGBT Health. 2014; 1(3):192–203. [PubMed: 26789712]
17. Hughes, T. Lesbians' use of alcohol: Methodological and sampling issues. In: Solarz, A., editor. Lesbian health: Current assessment and directions for the future. Washington, DC: National Academy Press; 1999. p. 79-84.
18. Hughes, TL. Sexual identity and alcohol use: A comparison of lesbians' and heterosexual women's patterns. Talk presented at: New Approaches to Research on Sexual Orientation, Mental Health, and Substance Abuse; 27 September 1999; Bethesda, MD.
19. Hughes TL, Haas AP, Razzano L, Cassidy R, Matthews A. Comparing lesbians' and heterosexual women's mental health: A multi-site survey. J Gay Lesbian Soc Serv. 2000; 11(1):57–76.
20. Solarz, AL., editor. Lesbian health: Current assessment and directions for the future. Washington, DC: Institute of Medicine, National Academy Press; 1999.
21. Hughes TL, Wilsnack SC, Szalacha LA, et al. Age and racial/ethnic differences in drinking and drinking-related problems in a community sample of lesbians. J Stud Alcohol Drugs. 2006; 67(4): 579–90.
22. Hughes, TL. Advances in research on lesbian health. Talk presented at: Congressional briefing sponsored by the National Coalition on Lesbian, Gay, Bisexual and Transgender Health; 2004; Washington, DC.
23. Hughes T, McCabe SE, Wilsnack SC, West BT, Boyd CJ. Victimization and substance use disorders in a national sample of heterosexual and sexual minority women and men. Addiction. 2010; 105(12):2130–40. [PubMed: 20840174]
24. Alvy LM, Hughes TL, Kristjanson AF, Wilsnack SC. Sexual identity group differences in child abuse and neglect. J Interpers Violence. 2013; 28(10):2088–2111. [PubMed: 23345571]
25. Wilsnack SC, Kristjanson AF, Hughes TL, Benson PW. Characteristics of childhood sexual abuse in lesbians and heterosexual women. Child Abuse Negl. 2012; 36(3):260–65. [PubMed: 22425697]
26. Wilsnack SC, Hughes TL, Johnson TP, et al. Drinking and drinking-related problems among heterosexual and sexual minority women. J Stud Alcohol Drugs. 2008; 69(1):129–39. [PubMed: 18080073]
27. Clark J. Furore erupts over NIH "hit list". Brit Med J. 2003; 327(7423):1065.